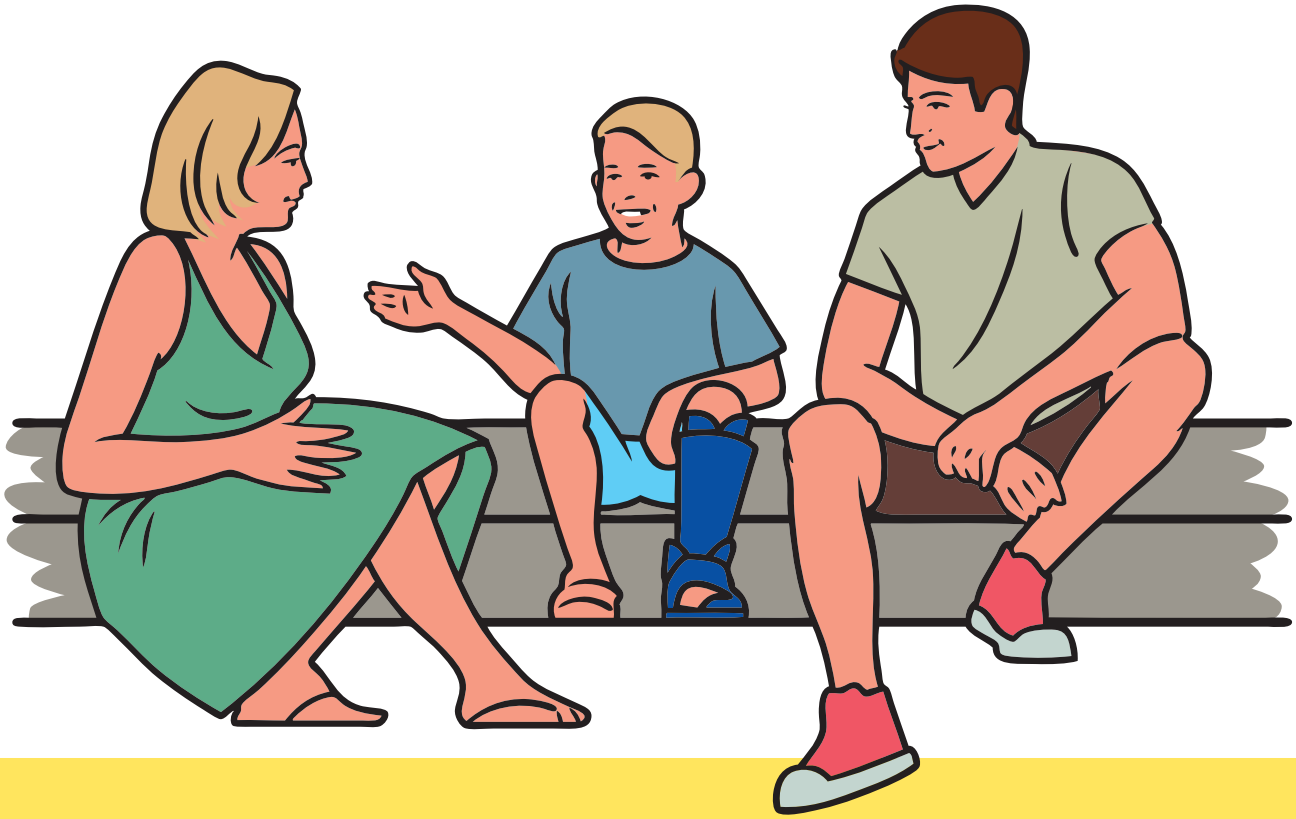
Evelina London

Stroke Association

Childhood Stroke



A handbook for families

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What is a stroke?

A stroke is when something goes wrong inside our brain.

Your brain is inside your head.

Your brain is the really clever part of your body.

It is in charge of your whole body.

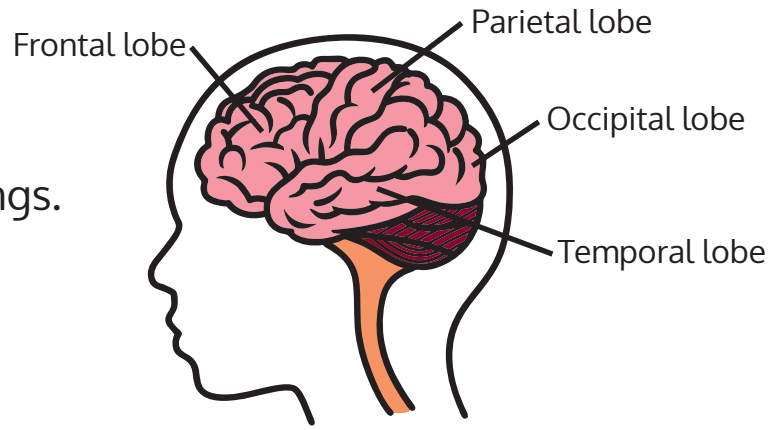
It helps you to think, talk, move and jump.

Your brain controls everything you do.

A bit like the hard-drive controls a computer.

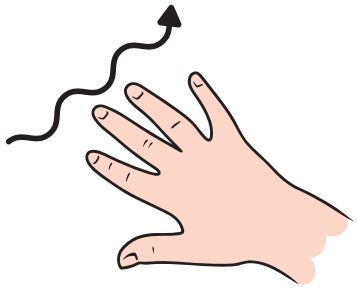
A bit like the remote controls a TV.

Different parts of the brain do different things.



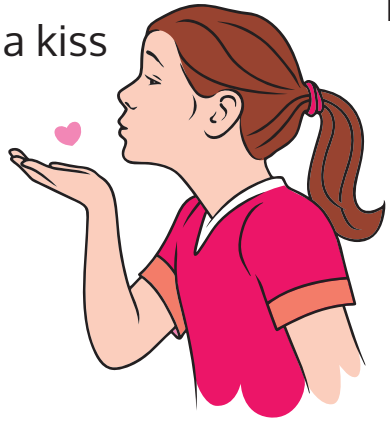
The brain has two sides and they control the opposite side of your body, so if you lift your left arm, the right side of your brain is making it happen!

You can see and feel your brain working all the time.

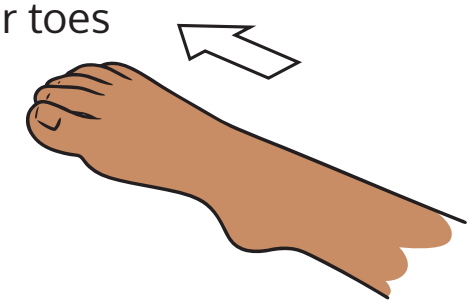


Wiggle your finger

Blow a kiss



Point your toes



Sing a song

Your brain helps you to do all these things –
it tells the muscles to move to make things happen.

The brain needs oxygen and energy to work well, a bit like how a garden needs water.

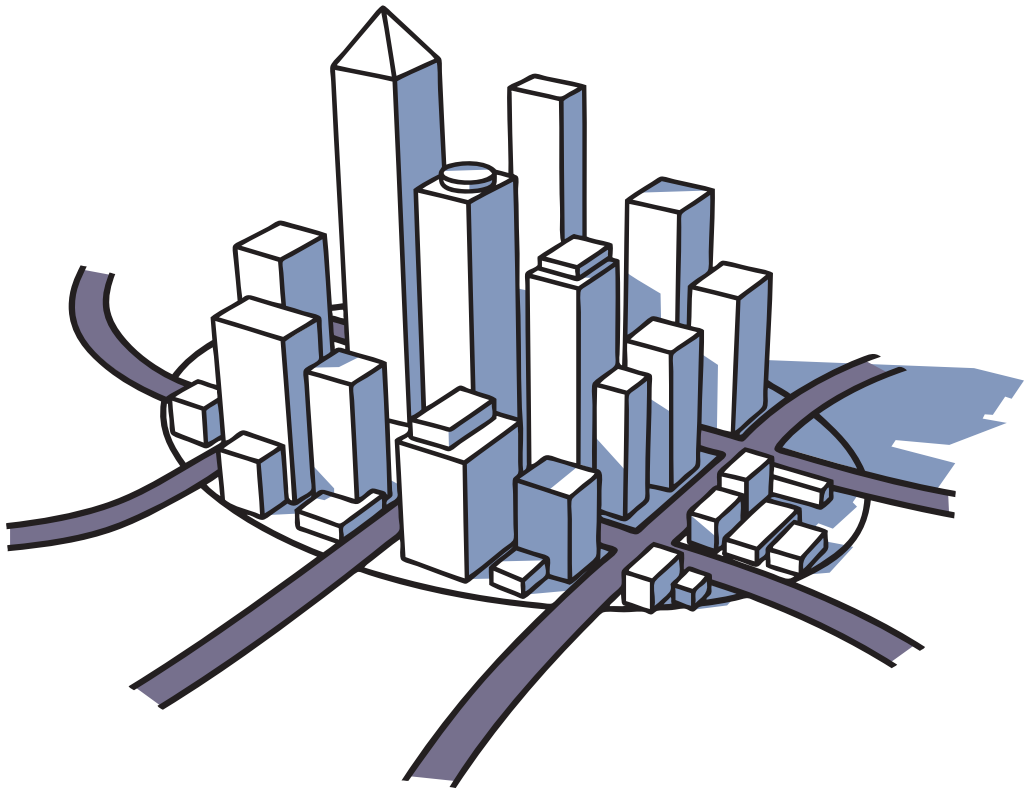
Or a bit like how a car needs petrol.

Your brain gets energy from your blood.

Which is pumped up from our heart.

It goes up to the brain through tubes called arteries and veins.

The arteries and veins are a bit like a network of roads, leading up to a big city: your brain!



There might be a blockage or a leak in the tubes leading to your brain.

If this happens your brain is not getting enough blood.

Without blood your brain does not get enough energy and oxygen.

When this happens you have a stroke.

It's a bit like if a car engine cannot get enough petrol, so the car stops working.

The part of your brain that is not getting enough energy and oxygen will find it hard to work.

If it is the talking part of your brain it may be hard to get the words out.

If it is the moving part of your brain it may be hard to move your arm or leg.

What does it feel like to have a stroke?

Children and young people describe having a stroke in different ways.

"One day I got wobbly and I fell over"

"I had a pain in my head and felt sick"

"My arm and leg did not work so well on one side"

"I could not feel very well on one side"

"I could not get the words out"

"I felt like I kept tripping over"

"I felt really tired and dizzy"

What happens when you have a stroke?

Going to hospital

If you have a stroke you might go to a hospital.

You might go in an ambulance.

You might go in to accident and emergency.

You go to hospital to find out what has happened.

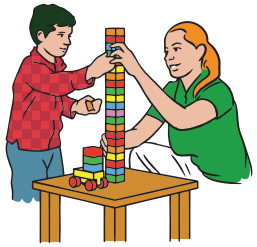
You might have to stay in hospital for a few days and nights in a big room which is called a ward.

You might be on a ward with other children – they could be all different ages.

What can help?

- You can take toys and games.
- You can put pictures and cards on the walls.
- You can wear your own clothes.
- People can come and visit you.
- Mum or Dad (or whoever looks after you) might be able to stay with you.

Who you might meet in hospital



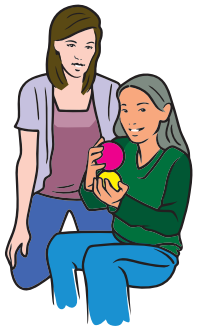
Play specialists
Help you to play and enjoy yourself

Doctors
Do lots of checks to find out what has happened and how to help

Nurses
Look after you on the ward

Psychologists
Help you to talk about what has happened and feel better

Radiologists
Do scans and x-rays to take pictures of different parts of your body. They help the doctors to understand what has happened



Occupational therapists
Help you get stronger, and back to doing the things you want to

Physiotherapists
Help you with your movement

What can help?

- Ask everyone to tell you who they are.
- Ask everyone to explain what they do.
- Maybe they can write down in a book or on a chart when they are coming back to see you.

Checks in hospital

The doctors might ask you to move in different ways.

This could be harder than usual if your body feels funny, but that's OK.
The doctors understand.

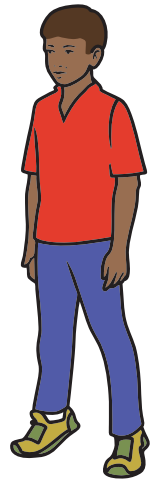
They might ask you to:

Lift your arms

Lift your legs

Stand on one leg

Walk on tip



Show how strong you are

Wrinkle your nose

Stick out your tongue

They might use a little stick to:

Tap your knees.
Tap your elbows.

They might look in your mouth and get you to say ‘ahhhhhhh’.

They are checking that your body is working OK.

They are checking that your brain is getting messages through to your body OK.

What can help?

- You can ask the doctor to show you what they want you to do.
- You can ask mum or dad to do it too.

Checks in hospital

You might have some checks done to help the doctors find out what has happened.

Looking at your blood
The doctors will want to check that your blood is working OK.

It's important to make sure it is not sticky and causing blockages in the tubes that go from your heart to your brain.

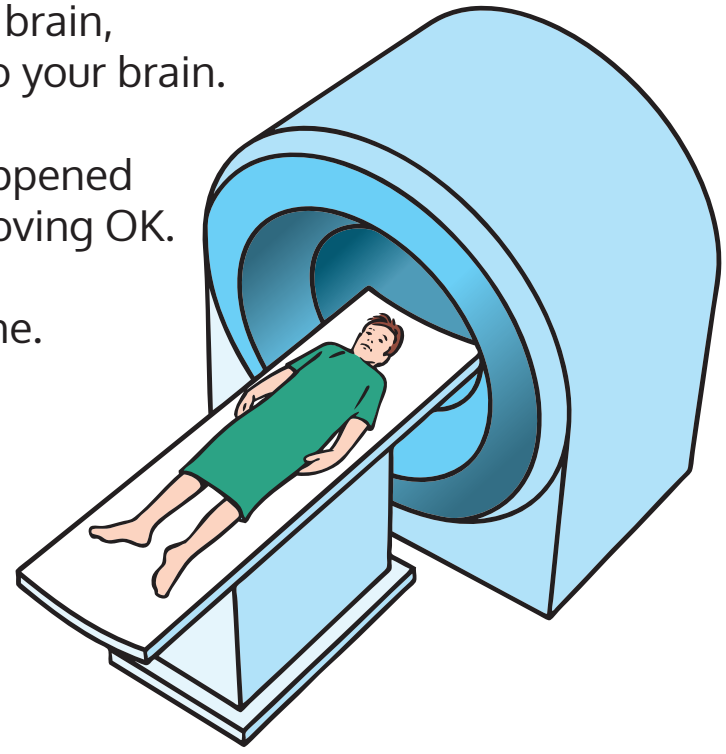
To do this, they might take some blood using a little needle – and then send it to be checked.

They will use cream or spray to make sure the needle does not hurt you.

Brain scans
The doctors might want to take a picture of your brain, and the tubes that carry blood from your heart to your brain.

This will show them exactly where the stroke happened in your brain, and make sure that the blood is moving OK.

To do this you will have to lie inside a big machine. It can be a bit noisy, and will take a little while. You need to keep still, but you can wiggle a small bit.



Heart scans
The doctors might want to make sure your heart is working well, and able to pump blood up to your brain properly.

To do this they might take a picture of your heart. You will be able to see it on the screen if you want to.

Blood pressure
The nurses might want to take your blood pressure. This will check that your blood is moving well through the tubes around your body. To do this they will put a little cuff around your arm (a bit like a swimming armband) and pump it up full of air and then slowly let it down.

Temperature
The nurses might want to take your temperature. This will check you are staying well.

To do this, they will put a little stick in your mouth or under your arm. You will have to keep it there for a few minutes.

What can help?

- You can make a plan with mum or dad about when you want to know about a test.
- You can ask to have a look at where the checks happen.
- You can ask to take a toy, or a book, or listen to music.
- You can make sure mum or dad is nearby.
- A play specialist might be able to make it more fun.

What would you like to do?

Why did I have a stroke?

There are lots of different reasons why children and young people have strokes.

When you have had all your checks, the doctors will look at the results.

They are trying to see why your brain did not get enough blood when you had your stroke.

It could be because:
Some of the tubes going up to your brain are a bit small and thin – so blood has been getting stuck there.

Some of the tubes going up to your brain are a bit tangled up – so blood has been getting stuck there.

One of the tubes going up to your brain had torn a little bit and so some blood leaked out.

Your heart was not able to pump blood up to your brain very well, and so your blood formed little 'sticky' clumps, that caused a blockage. Doctors call these clumps a clot.

You were having an operation to help your heart, but when this happened, some of your blood formed a little 'sticky' clump, caused a blockage.

Your blood is a bit 'sticky' and does not always flow smoothly and easily through the tubes in your body and that caused a blockage.

It could be that doctors cannot find out why you had a stroke.

Lots of children ask why they have had a stroke. If you have had a stroke, it is not your fault.

Lots of children worry it was something they did.

Some children worry it was because they were naughty.

This is not why a stroke happens (see section 1 to read more about this).

What can help?

- Talk to your mum and dad about the checks.
- Talk to the doctors.
- Ask lots of questions if you want to.
- Ask if you do not know what a word means.
- You can ask questions even a long time after the stroke.

Treatment

Sometimes you need medicine or treatments to keep well after a stroke.

Medicine

The doctor might talk to you about aspirin or warfarin.

These medicines help the brain to get a good supply of blood. They both work by making your blood less sticky.

You might need to have blood tests to make sure that the medicines are working well.

You might also need to have other checks from time to time – to see if you still need to take medicines.

The checks would be like the ones you had at the very beginning – taking pictures of your brain, or having blood tests or checking your blood pressure.

An operation

The doctor might decide you need an operation to make sure the tubes taking blood to your brain are working properly.

The doctor would talk to you about how the operation would work, and how long it might take. Before the operation the doctors would give you medicine to make you go to sleep, so it would not hurt.

What can help?

- Talk to your mum and dad and the doctors if you are worrying about taking medicines.
- You might be able to take them in different ways.
- You might be able to take them at different times of the day. You can also talk to the doctor about how long you might need to take medicine for.
- You might not always need to go to hospital for tests and treatment. Sometimes checks can be done near home or at home.
- It is important that you say if they make you feel funny.
- If you need an operation, talk to the doctors about it. Some people get a bit worried if they haven't had an operation before, but the doctor will tell you what will happen.

Staying well

There may be things that you cannot do for a while. Everyone is different.

Your doctor should talk to you about this.

You may need to:

Take medicines.

Have blood tests to make sure the medicines are working.

Rest more.

Stop playing sports or doing activities where you might bang your head.

Stop playing sports or doing activities where you twist your neck.

Not get too hot or cold.

Not get too tired.

Drink plenty of water.

Doctors will ask you to do these things so you stay well.

It is normal to be cross about some of these things and want to talk about them.

As time passes you can talk to the doctor about these things again.

What can help?

- It is OK to ask the doctors:
    - What sports can I play now?
    - Do I still need more tests?
- Talk to your mum and dad before your appointments.
- Make a list of all the things you would like to ask the doctor.

Getting better when you have a stroke

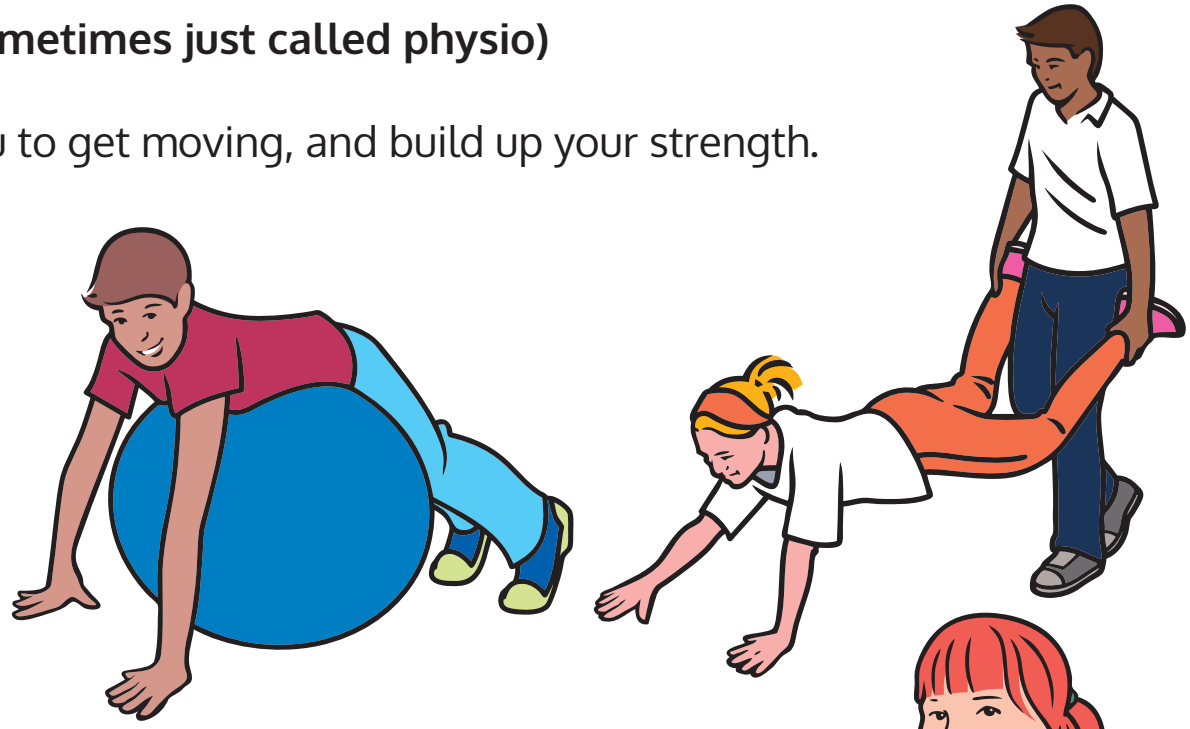
Therapy

When you have had a stroke you might need help to get stronger and feel better.

Here are some people who might help you:

Physiotherapist (sometimes just called physio)

Physios will help you to get moving, and build up your strength.



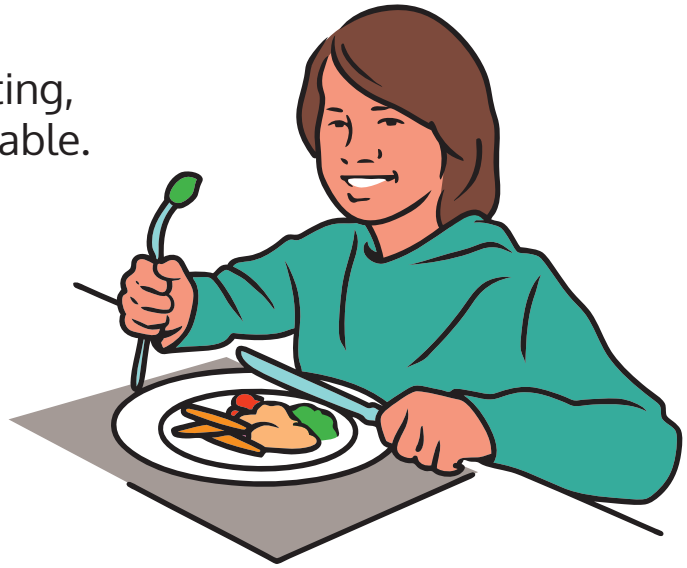
Occupational therapist (sometimes just called OT)

OTs help you to do everyday things, like getting dressed, getting washed, playing and managing at school.

Speech and language therapist (sometimes just called a SALT)

Speech therapists help you to communicate and chat to your friends and family.

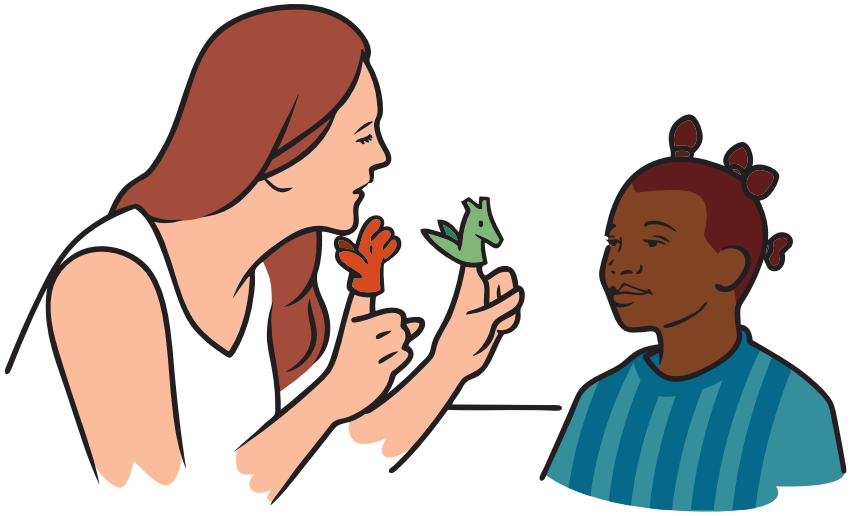
They can also help you make sure eating, drinking and swallowing are comfortable.



Play specialist

Play therapists help you to enjoy playing and learning.

They have lots of great toys and games.



Dietitian
Dietitians check you are getting enough to eat and drink, so that you have enough energy to get well. They might talk to you about special drinks, or extra food that can help make you stronger.

Psychologist
Psychologists help you to talk about your feelings. They might ask if you have any worries or questions. They can talk to other people in your family too.

All the therapists you meet will talk to you about how you are doing.

They will work with you to see what is difficult at the moment and decide how they can help.

They will talk to you about 'goals' – what you want to get better.

You will agree a plan together.

You may have to practice everyday.

What can help?

- It can help to decide what is important to you.
- Tell the therapists what you find hard so they can work out how to make it easier.
- Think about all the things you do at home, at school, when you are with friends, and at the weekend.

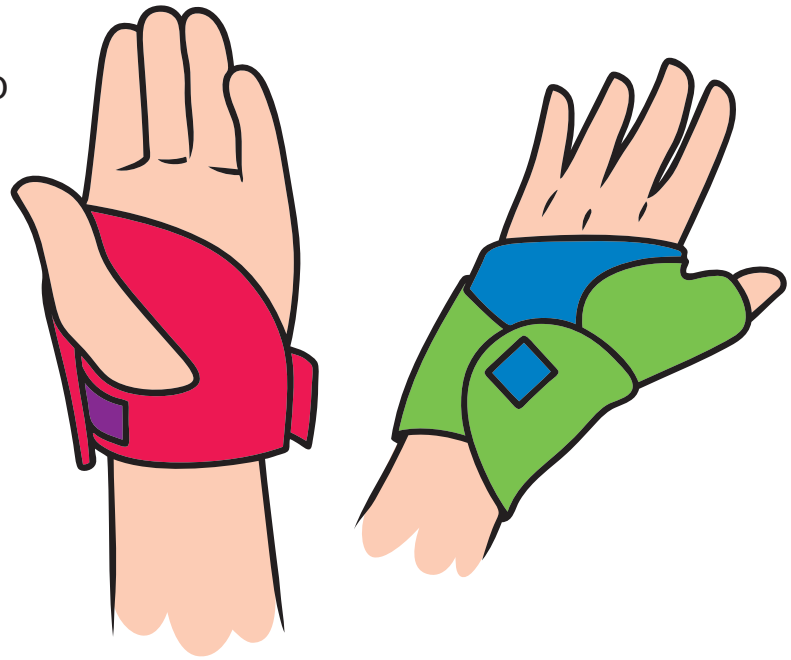
Equipment

Things that may help you.

When you have had a stroke, you might need some special equipment to help you.

Equipment can help with lots of different things you do every day.

Some children and young people wear hand splints. These can help to keep your hand comfortable, or to make it easier to do things.

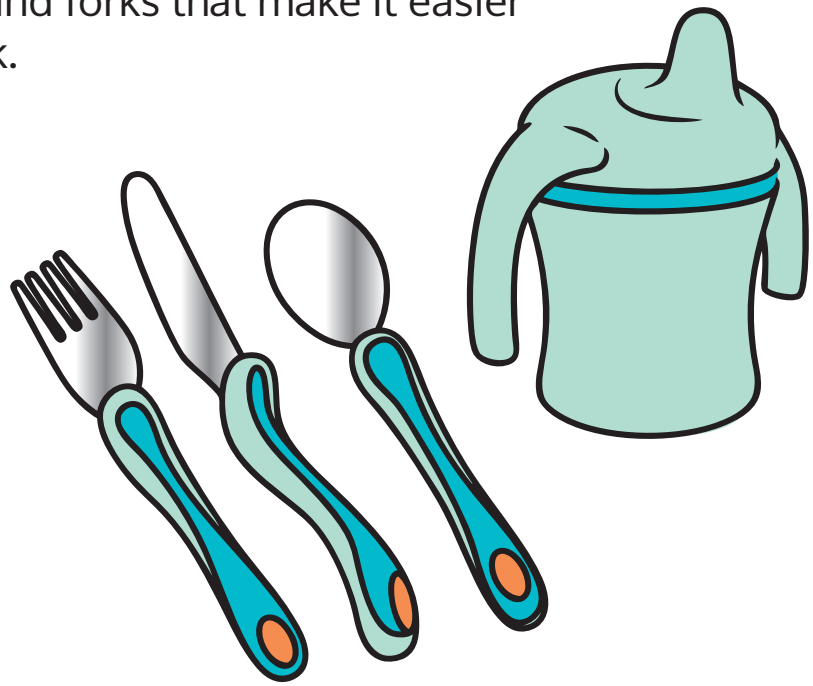


Some children and young people wear something called an orthosis or foot splint. These can help support their knee, ankle or foot when walking.

You might meet someone called an orthotist or podiatrist.

They might check your walking and your feet and that your splint is comfortable and working well for you. Some children and young people use a wheelchair to help travel around. This can help when they get tired or have to go a long way.

Some children and young people use special knives and forks that make it easier to eat and drink.



Some children and young people find it helpful to use special scissors and pen grips when they go back to school.

The therapists who you meet might try lots of different kinds of equipment with you.

Ask your therapist if you have any questions.

What can help?

- Say what you think.
- Tell them if it is not comfortable.
- Tell them if it helps you to do the things you want to do.
- Equipment comes in lots of colours and sizes.
  You can put stickers and transfers on it if you want to.

Feeling tired

After a stroke it can take a while for your brain to recover, and your body to feel better.

Lots of children and young people say they feel really tired even if they have had a good sleep.

Sometimes your arm or your leg may get tired or achy.

Sometimes your whole body may feel tired.

Sometimes you may feel sleepy.

Sometimes it may be hard to concentrate and listen to what other people are saying.

Noisy and busy places can feel tiring too.

Even watching TV and playing can be tiring sometimes.

This is normal.

What can help?

- Let people know that you are feeling tired.
- Get lots of sleep.
- Plan your day so you can have breaks from time to time.
- Plan your week so after a busy day you can have a rest day.
- Make sure you have enough to eat and drink – to keep your energy up.
- Talk to your doctors and therapists – they may have ideas that can help.

Going home

Some people leave hospital quickly.

Some people stay in hospital for a while, and then go home.

When you get home you may come back to the hospital for lots of appointments.

You may carry on seeing therapists like the physiotherapist or occupational therapist when you get home.

This might be a new team of people who work near where you live.

It might mean getting to know new therapists and doctors.
They will want to make sure you stay well.

You may be really excited to go home.

But you may be a bit worried too.

It can be nice to be back with your toys and your room.

It can feel different – if you are tired, or things are a bit harder.

You might have special equipment to make it easier to move about at home.

What can help?

- Some people like to plan ahead when they are going home.
- It might help to talk to your family about what you would like to do when you get home.
- You might want to just see your family.
- You might want to plan to see your friends.
- You might want to see lots of people.
- You can talk to your family, and decide what you would like to do.

Going to school

Lots of children and young people look forward to going back to school.

It can be great to see your friends and your teachers.

Some children feel a bit worried about going back.

It can be hard if you have been in hospital for a while.

It can be different, especially if you have missed some school.

It can be hard if you feel tired or not well.

It is normal to feel pleased about going back.

It is also normal to be a bit worried.

Your mum and dad and therapists will speak to the teachers at school to let them know what has happened.

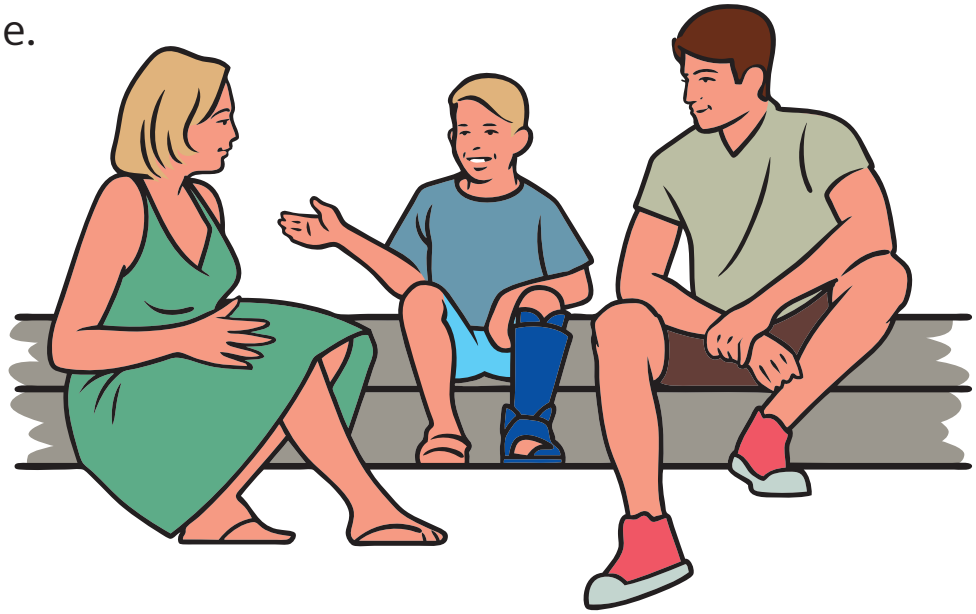
You may find therapists come and see you at school.

They may give you exercises or equipment to help you.

Your teacher may talk to you about how they can help.

You may get extra help from a classroom assistant.

It will be new for everyone.



What can help?

- Talk to mum and dad and your teachers if you are worried.
- Let people at school know what helps.
- It might be helpful to think about what you want to say to your teachers and classmates.
- Give yourself time to settle in.

My notes and log

It can be hard to see how far you have come.

Some children like to make a note of their progress.

Think about talking to mum, dad, brothers and sisters, friends and grandparents too.

Get someone to write down each time you feel happy you have made progress.

It might be good to have some photos or drawings of things you have done, or how you are feeling.

Talking about your stroke

My stroke

Children say different things about having a stroke.

After a stroke, some things may be more difficult for a while.

Some things will stay the same.

Maybe it is difficult to move your arm and hand like you did before.

Maybe you cannot walk as easily or move as quickly.

Maybe it takes a bit longer to get your words out or tell a joke.

People may notice some changes.

Some changes only your family may notice.

Some changes only you will notice.

Some changes you may feel inside.

Maybe you feel a bit more worried.

Maybe you get more tired.

Maybe you have to concentrate harder at school.

What can help?

- It can help to know that you are not alone. Stroke happens to other children and young people.
- It can help to talk to someone about the things that are worrying you.
- There are lots of people who can help.

Feelings

It can be a big shock to be in hospital.

It can be a big shock to be unwell.

It can be hard not to be able to do the things you like to do at home.

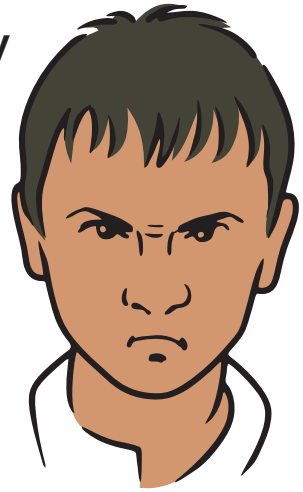
Lots of children talk about having lots of different feelings after a stroke.

You may feel:

Sad

Worried

Angry



Worried about your mum and dad.

Angry that you cannot do things.

Worried about what your friends think.

Glad to be getting better but wish it would be faster.

Worried about your brothers and sisters being left out.

Fed up of hospital and appointments.

Fed up of exercises.

It's OK to have all these feelings.

Sometimes it can be hard to say what you are feeling inside – you may just get really sad or really cross.

Maybe you will just be a bit quiet.

What about you?

What to do about feelings

What can help?

- Talk to mum and dad.
- Talk to a doctor.
- Talk to a psychologist. This is a doctor who is used to talking to children and young people about their feelings and worries.
- Talk to friends.

Make a plan about what to do:

Let someone know when you start to feel cross or worried.

Have a rest.

Have a walk.

Have a cuddle.

Talk things over.

Do something fun – draw, listen to music, play games.

Keep your energy up – ask for a drink and a snack.

It is OK to ask for help.

What can help? – have a think about your plan here

Brothers and sisters

This is a page for brothers and sisters.

It can be hard when someone in your family is in hospital.

It can be hard when they have to go to lots of appointments.

Sometimes your parents may not be at home.

Sometimes you have to stay with a relative or friend.

You might miss spending time with your family.

You might be worried that you will get sick too.

You might be worried about your mum and dad, and your grandparents too.

When your brother or sister comes home they may need extra care.

They might be tired.

They might find it hard to join in.

You might not be able to play with them like before.

You might not be able to chat to them like before.

What can help?

- Talk to your mum and dad about how you feel.
- Let them know if you are worried.
- You can ask questions too.
- Your brother or sister may need to do exercises and therapy, you can join in and help out.

Talking to other people

When you go home or go back to school:

People may ask you how you are feeling.

People may ask you what happened.

People may not know what a stroke is.

It is up to you who you want to talk to and what you want to say.

You may want to just talk to your family.

You may want to talk to your best friends.

You may want your class to know what happened.

It is up to you

You do not have to tell everyone all at once.

What can help?

- Talk to your mum and dad and other people in the family.
- It can help to talk to a teacher too.
- You can decide - what do you want people to know?
- Maybe some of the pictures and pages in these books will help explain things to people?
- Maybe you would like to make your own scrapbook of pictures and information?

Sickle cell disease

Some children and young people are born with a condition called sickle cell disease.

Sickle cell disease changes how your blood moves around your body.

Normal red blood cells are round and can move easily through the tubes in your body to get up to your brain.

When you have sickle cell disease your blood cells change shape and become long and thin. This means they are more likely to get stuck in the smaller tubes.

This can cause a blockage and make it hard for enough blood to get to your brain.

This can cause a stroke.

You will have all the same tests and therapy as other children and young people who have a stroke.

But you might have some different treatment.

Transfusions

The doctor might talk to you about having blood transfusions.

Some children need extra blood cells and the doctor will arrange for you to come in to hospital to have them each month.

The extra blood cells will help to stop your blood getting sticky or clotting too much.

Getting better

Sickle cell disease can make you feel tired, and can give you aches and pains.

It can mean that you will get infections and bugs more easily.

This can make it harder to feel better after a stroke.

Things that can help:

Talk to your mum and dad and doctor about anything that is worrying you or you're not sure about.

Let people know if you are tired – take a rest when you need to.

Let people know if it is painful to do your exercises and therapy.

Make sure you have enough to eat and drink.

Make sure you do not get too hot, or too cold.

Looking for more support or information?

The Childhood Stroke Support Service is available for children, families and young people affected by stroke in childhood.

The Service is a part of the Childhood Stroke Project – a collaboration between the Stroke Association and Evelina London Children's Hospital.

The service provides:

- Information about stroke in childhood and related diagnoses
- Advice about local services and follow-up that families may find useful
- Support navigating health, social care and educational processes
- Advocacy for young people and families in accessing the services they need
- Emotional support in adjusting to the impact of stroke
- Signposting to peer support networks for parents and young people
- Information for professionals supporting young people affected by stroke
- Information about events and awareness raising opportunities

If you would like to speak to someone for advice or support, please take a look at our website **www.stroke.org.uk/**childhood or call us on **0303 3033 100**

Evelina London

Stroke Association

Special thanks

With special thanks to Philip and Wendy Taylor for their generosity in supporting the development and publication of this booklet and also to those supporters, families, volunteers and of course children without whom it would not have been possible.

When stroke strikes, part of your brain shuts down.

And so does a part of you. Life changes instantly and recovery is tough. But the brain can adapt. Our specialist support, research and campaigning are only possible with the courage and determination of the stroke community. With more donations and support from you, we can rebuild even more lives.

Donate or find out more at **stroke.org.uk**

We're here for you. If you'd like to know more please get in touch.
Stroke Helpline: **0333 567 0841**
Website: **stroke.org.uk/gethelp**
Email: **info@stroke.org.uk**
From a textphone: **18001 0303 3033 100**

Rebuilding lives after stroke

Stroke Association

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